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Chronic breathlessness: re-thinking the symptom

To the Editor:

Is chronic breathlessness a symptom or a syndrome? Although hotly debated [1–5], we would like to suggest an alternative viewpoint. Here, we speculate that the argument over chronic breathlessness being considered as either a symptom or syndrome both holds us within a reductionist framework, and somewhat misses the point.

The approach of traditional medicine has been to identify and target the pathophysiology thought to underlie symptoms, and thus treat a disease. However, more modern neuroscientific approaches have taken a significant leap forward within our understanding of perceptual systems. First examined within the conventional, exteroceptive senses (vision, touch, *etc.*), the “Bayesian brain hypothesis” outlines how perception occurs as a result of a delicate balance between incoming sensory information and the brain’s predictions about the world around us, based on learned experiences (priors) (figure 1). This hypothesis has recently been applied with vigour toward a more abstract set of perceptions, which consider the monitoring of our internal sensations (termed interoception [6–8]), such as breathing [9, 10].

Thus, this framework emboldens us for a more comprehensive appreciation of the important point raised by CALVERLEY [5]; namely, understanding what illness means to the patient and how it affects their lives. Each individual brings their own set of prior expectations, interoceptive abilities and bodily awareness [11, 12] and, thus, breathlessness will be both vastly quantitatively and qualitatively different between individuals. The breadth of these differences cannot hope to be enumerated into a narrow, homogenous set of symptoms that fall within a customary definition of a “syndrome”, but that does not need to be what JOHNSON *et al.* [1] were trying to achieve. The point, instead, is to view breathlessness as something that might not directly correspond to airway pathophysiology, and which may need to be treated both in parallel and independently of the lungs.

Furthermore, this theoretical view of breathlessness does not simply stop at lung disease. Whilst descriptive differences are often apparent between individuals who experience breathlessness in health, lung disease and other breathlessness-associated diseases, there is unlikely to be a hard qualitative boundary that exists between these (sometimes transient) health statuses. The wealth of experiences and prior expectations brought to the table by even healthy individuals will evoke a spectrum of breathlessness perceptions, and may even alter an individual’s propensity towards symptom severity and debilitation, should they ever become associated with disease. Therefore, attempts to quantify even the intensity of breathlessness as a more purely physiological perception determined by neural respiratory drive, whilst appealing within a traditional reductionist framework, appears to be a significant oversimplification that moves us further from understanding breathlessness within an individual.

So where do we go from here? How do we tackle these seemingly infinite degrees of freedom and dimensions of breathlessness within an individual? Whilst phrenology was popular within the Victorian era, where different parts of the brain were assigned different functions, we must now update our methodology to equip us to test these current theories. Modern neuroimaging techniques allow us to envision cortical activity that may flow from areas such as primary motor/sensory cortices and posterior insula, relevant for primary signal transduction of afferent inputs, but we must tread carefully in labelling this “conscious perception”. Instead, perception (and indeed breathlessness) is likely to be an evolving



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Chronic breathlessness, symptom or syndrome: are we asking the right question?

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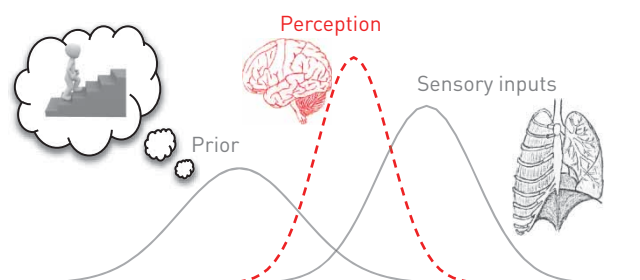


FIGURE 1 Schematic of the Bayesian brain hypothesis. Both prior expectations and incoming sensory information contribute to the resulting perception, where each is a distribution of possible values. Thus, both the precision and position of priors and sensory inputs can influence perception.

function embedded within dynamic brain networks, where transduced sensory inputs are continuously compared to the brain's model of the world. Thus, linear increases in activity within one brain area is not likely to produce a corresponding linear change in breathlessness, and we need to equip ourselves with appropriate computational strategies [13, 14] to tackle these more difficult, more multi-dimensional brain network models.

Therefore, the suggestion from CAMPBELL and HOWELL [15] that “a respiratory physiologist offering a unitary explanation for breathlessness should arouse the same suspicions as a tattooed archbishop offering a free ticket to heaven”, appears to have been a foreseen and apt word of caution to our modern neuroscientific selves. Indeed, to understand breathlessness we need to delve into the brain more deeply, requiring an understanding of the networks that generate perception, and not just correlated activity in single brain areas. In turn, this may lead us to identify important treatable traits relating to breathlessness, complementing periphery-based therapies across a host of diseases and disorders, and hopefully better address the holistic effect of an illness on the life of an individual.

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*From the authors:*

We agree with much presented in O.K. Faull and colleagues' response to our proposed chronic breathlessness syndrome and thank them for their views supporting chronic breathlessness as more than just a symptom [1]. In particular, we agree that naming and defining chronic breathlessness as a syndrome does not aim, or need, to constrain a recognition or understanding of quantitative and qualitative between-individual differences. We agree that our intention is to ensure patients and their families living with the daily disability affecting all domains of life, irrespective of cause, may legitimately bring this experience to the attention of health and social professionals, receive a systematic assessment and subsequently benefit from individually tailored evidence-based management.

There are two issues for comment. Firstly, O.K. Faull and colleagues appear to equate breathlessness with primarily a sensory, effective and cognitive perception. However, the foremost burden of chronic breathlessness is not sensory, but rather the functional confinement that breathlessness imposes on an individual. In chronic breathlessness, affective and cognitive perceptions relate more to loss of function, socialisation and fulfilment, and to fear of suffocation and death. Chronic breathlessness syndrome highlights that the impact of this condition reaches well beyond the unpleasant perceptions of, and emotional response to, a symptom into the realm of functional impairment and disability. This concept is illustrated well in recently published practical clinical assessment and management approaches to chronic breathlessness, the Breathing, Thinking, Functioning and Breathing SPACE models [2, 3].

Secondly, the use of the term reductionist is unhelpful as implied by O.K. Faull and colleagues, that is, a syndrome attempts the impossible; a complex idea cannot be completely understood in terms of its components and an attempt to do so is foolish. However, reductionist may also be used in the sense of analysing "complex things into less complex constituents" [4]. "Breathlessness persists despite optimal treatment and causes disability" [1] for many, yet remains almost totally invisible to most health and social care professionals. Therefore chronic breathlessness needs an identifiable profile in order to bring patient experience into view, help them access evidence-based interventions and stimulate research into the complexity of breathlessness in order to identify future therapeutic targets. Already, the work of O.K. Faull and colleagues has increased our understanding that perception of chronic breathlessness (experienced by patients) compared with that in healthy volunteer models is different; but much more research is needed [5]. If reducing the complex to recognisable components in clinical practice helps clinicians to routinely assess patients, helps patients have their concerns heard, helps carers to seek support and understanding, and helps services to develop and research to grow, then the reduction of chronic breathlessness to a syndrome will have made a major difference to the lives of many.

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To the Editor:

We wholly applaud the move by JOHNSON *et al.* [1] to improve awareness of breathlessness and to raise its profile as a subject for focussed clinical research. We consider their research and the ensuing proposal to recognise breathlessness *via* a new medical term, “chronic breathlessness syndrome”, as important and justified. We share their goal, which is to direct attention to this neglected, undertreated and under-researched symptom.

There are two important caveats to be made in response to this article, however. First, there is a need to involve those who live with chronic breathlessness and are thus “experts by experience” in discussions about the framework proposed here, rather than bringing them into the conversation once consensus has been achieved. Second, further medicalisation of breathlessness *via* the term “syndrome” may not be the best way forward. Research into patients’ experience of breathlessness shows that the ways in which breathlessness is spoken about (medicalised and otherwise) not only reflect their experiences but also helps to shape how breathlessness is lived [2–6].

O.K. Faull and colleagues, in their response to JOHNSON *et al.* [1], comment on the individuality of responses to breathlessness that rely on prior experiences and bodily awareness (interoception). Context and culture play an important role in shaping the understanding and perception of breathlessness [2–4, 6]. For example, among African American communities across the USA, the last words of Eric Garner, “I can’t breathe”, as he suffocated in a tussle with police officers, have become a slogan for the Black Lives Matter movement and a metaphor for the lives of those living under other kinds of oppression [2]. BAŞOĞLU [7] suggests that asphyxiation is the most traumatic form of torture and that persistent breathlessness because of an underlying medical condition may be even worse due to the duration of the suffering involved.

Sufferers of respiratory illness vary in relation to the intensity, affect, ideation and meaning they attribute to their breathlessness [3–6]. It affects every aspect of the life of a breathless person in ways that description of it as a medical symptom cannot capture in full [8]. There is a need to legitimise a range of attitudes towards breathlessness in order for them to inform the clinical encounter. Collecting such experiences under the umbrella term “syndrome” may not be sufficient to enable full expression of the variability and multiple meanings of the experience of breathlessness, and may carry unexpected cognitive and affective “baggage” that detracts from its utility as a proxy for experience.

In view of the highly contextualised experience of breathlessness, it is critical to think about whose views are part of the debate. Discussions with experts by experience and first-person reports of experiences of breathlessness [3, 5] have revealed how powerful language and context are in determining how people with breathlessness think about and experience their problem [4, 6], and how this influences what they might do. Words such as “pulmonary” and “rehabilitation”, for example, may negatively impact upon the uptake of one of the most effective interventions for breathlessness [6].



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People with breathlessness should be involved in renaming their condition as their experience can be influenced by clinical language <http://ow.ly/ZKNj30hzUUM>

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There is a further stage necessary in the research process of JOHNSON *et al.* [1] in order to validate the claim made in the paper that “a recognised syndrome would [...] give permission for patients to discuss their ongoing breathlessness with their clinicians”. As JOHNSON *et al.* [1] suggest, patients and their families need to be involved in the discussion, but they should be able to critique the framework suggested by the paper, rather than be presented with it as a *fait accompli*. Otherwise there is a danger that the words “chronic” and “syndrome” will drive people with breathlessness further underground, in part because they have not been involved in the process of describing their own condition [9]. We encourage JOHNSON *et al.* [1] to take this research on to its next logical stage, that of developing a truly consensual terminology that considers the critical role language, metaphor and meaning play in both living with and treating breathlessness. This could be done using the Delphi technique within a more participatory paradigm [10]. Such an approach offers the chance of empowering patients and caregivers in ways that would result in real changes to both their experience and treatment.

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